What if my baby has one of these disorders? Can it be cured?

Because most of these disorders are inborn genetic problems, they cannot be "cured," just as eye color or height cannot be permanently changed. However, the serious effects of the disorder can be lessened–and often completely prevented–if a special diet or other medical treatment is started early.

If one of my children has a disorder, will other children I have be born with it also?

This question is a very individual one. It can be answered only by a trained professional who has more information about your family's health history. Many families seek genetic counseling to help them understand why they happened to have a child with an inherited birth defect. They may also wish to discuss possible risks to their future children. If you would like more information about genetic counseling, your doctor or clinic will help you obtain it.

How can I make it easier for the doctor to help my baby?

If your doctor asks you to bring in the baby for retesting, do so as soon as you can. If your child does have a disorder, your prompt action in following the doctor's instructions can be very important. If you do not have a telephone, it will be helpful to leave the phone number of a friend, relative, or neighbor with the doctor. You can also help by notifying your doctor or clinic immediately if you move soon after the baby is born. Inform them of your new address and telephone number. Then, if your child should need to be retested for any reason, your doctor will know where you can be reached.

Remember, time is of great importance. As a parent, you can help to assure the health of the new generation by your cooperation with the Newborn Screening Program.

Birth Defects Identified by the Kansas Newborn Screening Program

Phenylketonuria (FEN-nil-KEE-tone-u-ree-ah), also called PKU. A component of food protein (phenylalanine) cannot be broken down by the body due to lack of a chemical (enzyme). Brain damage, which would normally result, can be prevented by a special diet low in phenylalanine. PKU occurs in about 1 of every 12,000 newborns.

Galactosemia (ga-LAK-toe-see-me-ah). A milk sugar (galactose) cannot be broken down by the body due to the lack of an enzyme. A diet low in galactose can prevent life-threatening complications. Occurs in about 1 of every 60,000 newborns.

Hypothyroidism (HIGH-poe-THIGH-royd-ism). Inadequate production of a hormone (thyroxine) can lead to mental and growth retardation. Treatment is daily thyroxine tablets. Occurs in about 1 of every 4,000 newborns.

Hemoglobinopathies (HE-ma-glow-bin-o-path-ease). Presence of an unusual hemoglobin. Most unusual hemoglobins do not require treatment. Sickle cell disease is an unusual hemoglobin that requires antibiotic treatment to prevent life threatening infections.

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Newborn Screening For Your Baby's Health

The Kansas Newborn Screening Program is a service provided by the Department of Health and Environment to families with newborn babies in conjunction with participating doctors and hospitals. This program is responsible for testing every infant within a few days after birth for specific disorders.

Why is my baby tested?

A simple quick, and economical blood test provides important information about your baby's health that you or even your doctor might not otherwise know. The Newborn Screening Program identifies the few infants who may have one of the rare birth defects and alerts the doctors to this possibility. With early diagnosis and medical treatment, mental retardation or serious illness can usually be prevented.

When will my baby be tested?

The specimen will be taken before your baby is discharged from the hospital.

How is my baby tested?

All of the tests are performed on blood spots obtained by pricking the baby's heel. The blood is collected and allowed to dry on a piece of special filter paper, which is sent for testing to the Department of Health and Environment.

Is newborn screening a new procedure?

No, it is not new. Every state in the United States has a newborn screening program. The Kansas program began in 1965 with phenylketonuria testing. More tests have been added since then.

How many disorders is my baby tested for?

There are four: phenylketonuria, congenital hypothyroidism, galactosemia, and hemoglobinopathies. Although these disorders are rare, they are usually serious. Some may be life-threatening. Others may slow down physical development, cause mental retardation, or lead to other problems.

The disorders can affect a child very early in life, some in the first few days or weeks of life, and others within the first few years. For this reason, early diagnosis and treatment are important.

But my baby seems very healthy. Are the tests still necessary?

Yes, the tests are necessary. Most infants with disorders identified by the Newborn Screening Program show no obvious signs of disease immediately after birth.

With special laboratory tests, the Newborn Screening Program can identify the infant who may have one of the disorders and can alert the doctor to the need for special care of the infant. Usually this can be done before the problem has time to cause damaging effects.

But we never had any birth defects in our family.

Parents who have already had healthy children do not expect any problems with birth defects, and they are almost always right. These disorders are quite rare, and the chances are excellent that your child will not have one of the disorders. However, the few children who are born with these problems are generally from healthy families. By testing every baby after birth, we can be sure that each infant who has a disorder will be identified and started on early treatment.

How much will these tests cost me?

No charges are made for these tests by the Department of Health and Environment. A charge may be made by the agency obtaining (collecting) the specimen.

Will I be told if the tests show no birth defects?

Your doctor or hospital will be informed when the test are completed. Generally, the doctor notifies the parents if there is a problem, but you can ask about the results when you bring your baby to the doctor or clinic for regular check ups.

Although "no news is usually good news," it is important to remember that these tests provide information only about four rare disorders. Even if an infant is free of these disorders, there may be other medical problems for which we cannot test by these methods. It is very important for your baby to have regular check ups and good general medical care even when well.

Does a "retest" mean my baby may have a birth defect?

Not necessarily. On the rare occasions when the first tests indicate a possible problem, the results are not considered final.

Instead, a new blood sample is requested and the tests are repeated. As a general rule, only when a child's test is unusual for a second time will the doctor discuss the need for further evaluation. Only on very rare occasions, because of the potential severity of a particular disorder, will the doctor insist on treating the child immediately while waiting for the results of diagnostic tests.

If you are asked to have your child retested, please act quickly so the repeat tests can be completed and final results obtained while the baby is still very young.